

First Words

A First Steps Communications Tool for Families From Family to Family

“...Prepare for meetings and case conferences by writing down what you want to see for your child.”

Alphabet Soup

Each month we will cover a few abbreviations or acronyms parents might hear or see while in First Steps. Sometimes it is awkward for families to ask. Do you know these?

- **NICU = Neonatal Intensive Care Unit**

hospital care unit for premature and other high risk infants

- **ROM = Range of Motion**
the normal range of movement for a joint, including flexion (how far it can be bent) and extension (how far it can be stretched out)

- **ADL = Activities of Daily Living**

age appropriate activities related to personal care, which may include bathing, dressing, getting in or out of bed, toileting, eating, etc.

Skills for the Effective Advocate

As an advocate for your child in early intervention and special education, you will work to ensure that he or she gets the most appropriate services and education under the Individuals with Disabilities Education Act. You learned in last month's newsletter that an advocate is someone who pleads, speaks or argues in favor of; in this case, your child's right to a free appropriate public education. Pete and Pam Wright are leading educators in the area of advocacy. They conduct numerous trainings every year and have written several books on the subject. Their website, <http://www.wrightslaw.com> is a great resource.

According to Wrightslaw, an advocate possesses six important skills. The first is to **gather facts and information**. As an advocate, you need to have facts about your child's disability, developmental history and educational history. Documentation based on facts is going to help you resolve issues and negotiate more effectively than documentation based on emotion. The second skill is to **learn about the system and your rights**. Learn who the personnel are that will be part of your child's team; they, along with you, make the decisions about your child's services or education. Attend an Article 7 (Indiana's version of IDEA) training, call IN*Source for advocacy assistance, and/or talk with other parent advocates to help you increase your knowledge. Skill number three is to **plan and prepare**. Plan ahead by becoming educated about your rights. Prepare for meetings and case conferences by writing down what you want to see for your child. You may even find it helpful to fill out your version of the IFSP or IEP form ahead of time with objectives you would like to see included. The fourth skill needed by an effective advocate is to **keep written records**. All requests for testing or other services need to be in writing. Anything said to be included in the IFSP or IEP at the conference must be in writing in the document. Don't assume a verbal agreement will hold up. The fifth skill is to **ask questions and listen to answers**. Don't be afraid to ask questions, but be sure to listen carefully to answers. You will likely learn a lot about the positions of members on your child's team. **Identifying problems and proposing solutions** is the last skill. Advocates recognize when problems arise but they don't waste time blaming others. Use negotiating skills to come to agreement and create a situation where both sides feel they've won something. You must be willing to pick your battles and let some things go.

Stay tuned for more. Next month we'll discuss how to talk so people will listen.

For more information about Family to Family, visit our web page at http://www.in.gov/fssa/first_step/f2f/index.html. You may also call 1-800-396-7188 or email family2family@sbcglobal.net.

Accessing Books and Videos at the Center for Disability Information and Referral (CeDIR)

In an effort to better serve Hoosiers with disabilities, their families and professionals, a specialized lending library collection of over 8,000 disability-related materials has been added to IUCAT, the Indiana University libraries' online catalog. The collection, housed at the Indiana Institute on Disability and Community, a research center on the Bloomington campus of Indiana University, is comprised of holdings that include topics that address a wide variety of disabilities, mental health, early childhood, school inclusion, behavior supports, and much more.

Materials from the Institute's collection can be borrowed by any resident of the state of Indiana. Items can be requested through interlibrary loan from local public libraries or directly from the Institute by telephone (toll free in Indiana at 800-437-7924 or 812-855-9396

in Bloomington) or e-mail (cedir@indiana.edu). Both telephone lines are equipped with a TTY for people with hearing impairments or communication disorders. Individuals seeking additional assistance can contact the Institute at the numbers provided.

Items can be borrowed for four weeks. Requested materials can be borrowed via interlibrary loan through local public libraries or sent directly to a borrower's home or business address. The only charge to the individual may be to return the materials to the Institute at the end of the loan period.

The online catalog can be searched on the World Wide Web at <http://www.iucat.iu.edu>. When conducting a search, the "Select Library" box should read "Blmgtn – Indiana Institute on Disability (B-CeDIR)" to search for materials from the Institute's collection. Individuals who don't have personal computers can access the web at their local public library. The "HELP" button on the red toolbar provides detailed instructions for searching IUCAT.

The lending library is part of the Center for Disability Information and Referral (CeDIR), one of the seven centers located at the Indiana Institute on Disability and Community. For more information on what CeDIR provides for Indiana residents. Visit their website at <http://www.iidc.indiana.edu/cedir>.

Advocacy Tip of the Month

If you are passionate about promoting change and are a person with a disability or the parent of a child with a disability, you should apply for Partners in Policymaking. This program teaches participants to become effective advocates for people with disabilities in their communities.

"We arm participants with information they can use to help not only themselves but also other members of their communities," said Mike Foddrill, PIP Director. "It's not for you alone. It's how to be successful with the media, lawmakers, school boards and more."

Participants complete intensive training over eight weekends, from October through May, learning about advocacy topics such as the history of the disability rights movement and community inclusion. Other topics include legislation and lobbying, special education, social services, employment and community organizing.

"We really encourage people from all over the state to apply," Foddrill said. Over 500 Hoosiers have graduated from the program since its inception. The program is open to a limited number of people. If selected, hotel, travel, childcare and other related expenses will be covered by the program.

For a brochure or an application, contact the Partners office at (317) 232-7771, (866) 234-1635 (voice mail) or PIP@gpcpd.org. Or, visit www.in.gov/gpcpd and click on "Council Projects." Applications must be postmarked by Friday, June 3.

Resources for Families and Providers

Check out these resources for funding uncovered services:

First Hand Foundation

<http://www.firsthandfoundation.org>

National Autism Association Helping Hand

<http://www.nationautismassociation.org/helpinghand.php>

JT's Hand

<http://www.jtshand.org>

Helps with the expenses incurred while a child is in a Neonatal Intensive Care Unite (NICU).

Disabled Children's Relief Fund

<http://www.dcrf.com>